



Personal health budgets mandatory data collection guidance

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Personal health budgets mandatory data collection guidance

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Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

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2 This document

This document provides guidance for all clinical commissioning groups (CCGs) in England regarding the completion of the mandatory personal health budgets data collection being implemented on a quarterly basis from July 2018 onwards. This data is being collected by NHS Digital.

This guidance replaces all previous NHS England guidance regarding the collection of personal health budget data.

What information is being collected?

- The total number of people with a personal health budget being provided by your CCG on the first day of the quarter
- The personal health budget activity during the quarter
- Cumulative in-year personal health budget data, to align with the NHS Mandate expectations
- The model people are choosing to manage the budget **Sub group data:** Information on which groups of children and adults are receiving personal health budgets, which may overlap. This information is based on the financial YTD.

3 What is a personal health budget?

A personal health budget is one way of personalising people's care to ensure they get the care they need. A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team, or with a partner organisation on behalf of the NHS (e.g. local authority). Personal health budgets are not new money, but may mean spending money differently to ensure that people get the care they need The right to have a personal health budget currently only applies to adults receiving NHS Continuing Healthcare and children in receipt of continuing care, but all areas of England are being encouraged to offer personal health budgets more widely to other patient groups who could benefit.

For people to have a personalised and integrated approach to care a **person** should:

- Be able to access information and advice that is clear and timely and meets their individual information needs and preferences
- Experience a coordinated approach that is transparent and empowering
- Have access to a range of peer support options and community based resources to help build knowledge, skills and confidence to manage their health and wellbeing
- Be valued as an active participant in conversations and decisions about their health and wellbeing

- Be central in developing their personalised care and support plan and agree who is involved
- Be able to agree the health and wellbeing outcomes* they want to achieve, in dialogue with the relevant health, education and social care professionals

If this leads to a personal health budget, a person should:

- Know upfront an indication of how much money they have available for healthcare and support
- Have enough money in their budget to meet the health and wellbeing needs and outcomes* agreed in the personalised care and support plan
- Have the option to manage the money as a direct payment, a notional budget, a third party budget or a mix of these approaches
- be able to use the money to meet their outcomes in ways and at times that make sense to them, as agreed in their personalised care and support plan

To be able to count as a personal health budget the six key features **in bold and a larger font** above need to be in place.

Reminder: The data counted in this data collection only relates to the number of personal health budgets that have met all the 6 features above. This is important to ensure there has been a genuine shift in choice and control to individuals. If you are unsure of what you should be counting please contact your NHS England regional personal health budget lead or Kerrie Weston in the national team.

Managing the money

Personal health budgets can be managed in three ways (or a combination of these):

- Notional budget: the money is held by the NHS and services are commissioned by the NHS according to the support plan agreed.
- **Third party budget:** organisation independent of the person, the local authority and NHS commissioners manages the budget and is responsible for ensuring the right care is put in place, working in partnership with the person and their family to ensure the agreed outcomes can be achieved.
- **Direct payment for healthcare:** A direct payment is a monetary payment to a person (or their representative or nominee) funded by the NHS, to allow them to purchase the services that are agreed in the care plan.

More information on the underpinning regulatory requirements of all personal health budgets can be found on the NHS England <u>website</u>.

^{*}and learning outcomes in the case of children and young people

4 Frequently asked questions about completing the data collection

4.1 Should we count notional budgets, or only third party and direct payments?

All three kinds of budgets should be counted. The key question to ask is whether the six key features of a personal health budget are in place. Personal health budgets can be offered as notional budgets, third party payments or direct payments, all of which should be counted in the data collection.

4.2 If a person has both a notional element and a direct payment element, how many times should we count them?

4.2.1 Total (questions 1 and 4 – see Annex A)

Where an individual's personal health budget includes both a notional element and a direct payment element, they should only be counted once in questions 1 - 4. It is the person who should be counted, including if their budget is managed in more than one way. For example, if part of a person's NHS Continuing Healthcare (CHC) package is covered by a notional budget and another element covered by a direct payment, this should count only once in the CCG total.

4.2.2 Breakdown (questions 4a, b and c – see Annex A)

For the breakdown of how the budget is delivered (questions 4a, b and c) all methods of delivery should be counted in the relevant breakdown box of the total. For example, if a person is receiving a personal health budget as a direct payment for part of the package and via a notional budget for another part of their package, this should be recorded in both the direct payment section and the notional section of the question.

4.3 Should we count people receiving joint-funded packages?

Yes. If a CCG is contributing NHS funding to a social care or education package, there is a health need identified, and the six essential features of a personal health budget are in place, this should be counted as a personal health budget. This may be via a Section 75 agreement or another joint funding arrangement. Some examples of this may be for people with learning disabilities, or when carers receive some joint funding to meet their identified health needs.

Where a person has a joint funded package of care or a social care package and also receives NHS community based care, this aspect of the care should only be

counted as a personal health budget where the six key features are met including the option of a direct payment.

4.4 Should people be counted if the personal health budget was only for part of the package, or was given on a one-off basis?

Yes. All personal health budgets should be counted.

As part of reporting on activity data, (see Annex A questions 1-3) a one off personal health budget should only be counted in the quarter that the personal health budget was delivered and should be reported as part of the number of budgets that started (question 2) and ended within that quarter (question 3).

As part of reporting on cumulative data (please see Annex A – questions 4-15) all personal health budgets should be counted if they were provided at any time in the financial year to date.

4.5 At what point in time can a person be counted?

Notional budgets: Where a person has a notional budget, the personal health budget is considered to be in place at the point at which the care plan and budget have been agreed with the person, and the planned services have been arranged.

Third party and direct payments: Where a person has a direct payment or a third party budget, the personal health budget is considered to be in place once the amount of the direct payment or third party budget has been agreed with the person, and all the relevant processes for setting up the direct payment or third party budget have been completed. (This is the point at which the NHS has taken every action needed to put the direct payment or third party budget in place, and where any delays to the client actually receiving the payment are not within the control of the NHS.)

If a personal health budget is being delivered using a pre-paid card, the personal health budget would be considered to be delivered as a direct payment as long as the card can be used freely as agreed in the plan without any restrictions on what service or item it can be used for. Pre-paid cards and e-marketplaces should not be the only available option for people to receive a direct payment. There should always be the option of receiving a direct payment into a conventional bank account. If the option to receive the direct payment in to a back account does not exist then this cannot be counted as being a Direct Payment.

4.6 Should you count personal health budgets for people in residential care?

Yes, if the six key features of a personal health budget are met including the option of a direct payment.

4.7 Who should complete the data submission?

One person from each CCG should complete the data submission, however, you may need to involve more than one person in your CCG to gather the information required. For example personal health budgets may be being delivered by colleagues working in your mental health trust or by social care colleagues in joint funded services e.g. learning disabilities. Please ensure that the lead manager for personal health budgets at the CCG has reviewed and agreed the content before it is submitted to ensure all personal health budgets are being counted.

4.8 What if we are implementing personal health budgets in more than one CCG?

Each CCG should complete the data submission separately. As part of 2017/18 – 2018/19 planning round, each CCG was required to submit local personal health budget trajectories. This data collection will help monitor progress towards these trajectories and show progress on personal health budgets for people living in each CCG area.

4.9 What cannot be counted?

If the six key features are not met, this cannot be counted as a personal health budget. There should be a health outcome identified (in some instances this may be a preventative health outcome) and health funding included within the personal health budget. If these are not in place then it cannot count as a personal health budget. Personal Maternity Care Budgets cannot be counted within this data collection at this point as they are a different model of delivery.

4.10 Can personal wheelchair budgets be counted?

Since April 2017, all CCGs have been expected to start developing local personal wheelchair budget offers to replace the current wheelchair voucher system, as part of personal health budget rollout plans.

Personal wheelchair budgets can be counted in this data collection but should not be included separately in the total figures if the person is already receiving a personal health budget e.g. through Continuing Healthcare. This collection counts the number of people with a personal health budget rather than the number of separate budgets they may receive from different NHS services. The intention is that people will have

one care plan that includes all health needs rather than be delivered via a number of care plans and service silos.

Direct payments are currently not routinely available as an option for managing a standalone personal wheelchair budget. NHS England and the Department of Health and Social Care are currently reviewing existing regulations to establish whether additional contributions are permissible under the Direct Payments in Healthcare Regulations. Therefore where a direct payment is requested it would either need to meet the whole cost of the wheelchair (which may be appropriate as part of an NHS Continuing Healthcare package), or be part of an integrated package of care and clearly able to demonstrate the health and wellbeing outcome which required a contribution via a separately commissioned service.

Personal wheelchair budgets can be counted in the 'other' section of the voluntary section of the data collection. When considering if the personal wheelchair budget can be counted throughout the year and when to only count in one quarter the following should apply:

 A personal wheelchair budget can count as an ongoing personal health budget if annual reviews are being done A personal wheelchair budget can count as a one off if money for the wheelchair and agreed number of years' maintenance is paid as a lump sum and no reviews are taking place.

Further information on wheelchair budgets and the full range of deployment options available can be found on the personal health budget learning network.

4.11 Can I count a person more than once in the subgroup sections of the data collection?

Yes, the totals from the subgroup questions do not need to add up to the totals in the mandatory collection. This data is intended to provide further information about the groups of people who are receiving personal health budgets, so people may fit into more than one group. For example, an adult who is eligible for NHS Continuing Healthcare and has a learning disability would be counted in both of the relevant questions.

4.12 What age is a person considered an adult?

In the sub group section of the data collection anyone over 18 years is considered an adult and should be included in the total adult question (question 10). However, if someone over 18 is receiving an Education, Health and Care Plan (EHC), they can be counted in the EHC question (question 7) as part of the breakdown and in any other adult question within the voluntary section (e.g. Adult NHS Continuing Healthcare question 10).

4.13 Are there any information governance implications of sharing this data with NHS England?

No personal data is being requested as part of this data collection, just counts of individuals receiving personal health budgets depending on condition. The numbers are only being requested and collated at a CCG level and above.

If there are any concerns that the numbers in the table could lead to re-identification of any individual, further advice should be sought from your local information governance lead prior to releasing this information to NHS England. If a decision is made not to provide this information, due to risk of re-identification, NHS England should be informed of this.

5 Why is NHS England collecting the data and how will it be used?

The NHS Mandate sets an ambitious objective that between 50-100,000 people will have a personal health budget by 2020/21. The Planning Guidance for 2017/18/18/19 required CCGs to submit trajectories for the numbers of personal health budgets to be in place by end 2019. The data collected here on quarterly activity will be used to monitor progress against these trajectories.

Personal health budgets are included in the <u>CCG Improvement and Assessment Framework 2016/17 (IAF)</u>. For detail, please see item 105b on page 22 of the IAF Technical Annex.

This data submission will be used as a measure for the IAF on a quarterly basis. This is published on MyNHS. NHS England will use the national headline data in a variety of ways including in internal and public reports/publications. CCG level data will be used internally to update regional and NHS England teams to inform CCG assurance. CCG level data will also be sharedwith other relevant NHS England programmes e.g. Transforming Care.

People in receipt of NHS Continuing Healthcare have the right to have a personal health budget. This is not the right to a direct payment as the standing rules state, (Responsibilities and Standing Rules) (Amendment) Regulations 2013). NHS England and CCGs must be in a position to commission such services by means of a personal health budget that can be managed in one or more of three ways. Counting the number of personal health budgets in NHS Continuing Healthcare monitors progress. The number of direct payments compared with other models (notional or third party budgets) provides a proxy measure of the quality of the personal health budgets on offer.

6 Who can I contact if I have more questions?

For any questions relating to what information to include within the data collection, please visit the personal health budget learning network that provides a dedicated Q&A section. Alternatively, please contact Kerrie Weston (kerrie.weston@nhs.net) Personalisation Manager in NHS England's Personalised Care Team.

In addition to answering any questions received directly, NHS England will consider whether it would be helpful for that question and answer to be shared on the personal health budget learning network. If you have a question, looking on the learning network may give you the answer without having to email Kerrie.

Annex A: PHB data collection

Please note: The total number of personal health budgets for **adults and children** in your CCG should be reported.

Reminder: Only count those personal health budgets where all six key features have been met. A person must:

- Be central in developing their personalised care and support plan and agree who is involved
- Be able to agree the health and wellbeing outcomes* they want to achieve, in dialogue with the relevant health, education and social care professionals
- Know upfront an indication of how much money they have available for healthcare and support
- Have enough money in your budget to meet the health and wellbeing needs and outcomes* agreed in the personalised care and support plan
- Have the option to manage the money as a direct payment, a notional budget, a third party budget or a mix of these approaches
- be able to use the money to meet their outcomes in ways and at times that make sense to them, as agreed in their personalised care and support plan

The totals in the subgroup section of the collection (i.e. Adult CHC and Adult mental health) do not need to add up to the total adult or total children questions at the head of these sections. We are interested in understanding which groups of people are receiving PHBs, and these may overlap. For example, an adult who is eligible for NHS continuing healthcare and has a learning disability would be counted in both of the relevant questions.

This document is for reference only and should not be completed. NHS Digital will provide log on details to allow the data submission.

Quarterly data	Total number
Total Number of people with an open Personal Health Budget on the first day of the Quarter	
2. Personal Health Budgets Started in Quarter	
3. Personal Health Budgets Ended in Quarter	

Cumulative Data	Total number	Delivere d as a Direct payment	Deliver ed as a third party budget	Deliver ed as a notiona I budget
4. Cumulative Personal Health Budgets Year To Date (YTD)				

Subgroup data - Children and young people	Total number	Delivere d as a Direct payment	Deliver ed as a third party budget	Deliver ed as a notiona I budget
5. Total number of children and young people with a personal health budget for your CCG in the period.				
6. How many children receiving continuing care had a personal health budget in the period? Include in this section children who received continuing care funding for all or part of their care.				
7. How many children and young people with education, health and care plans had a personal health budget in the period? Include in this section children and young people who have statements or Education, Health and Care plans.				
8. How many children whose primary need is a learning disability and/or autism had a personal health budget in the period?				
9. How many other children had a personal health budget in the period? Include in this section children who are not receiving continuing care funding and who do not have an education, health and care plan. Other children with joint funding could be included here.				

Subgroup data - Adults	Total number	Delivere d as a Direct payment	Deliver ed as a third party budget	Deliver ed as a notiona I budget
10. Total number of adults with a personal health budget for your CCG in the period.				
11. How many adults receiving NHS continuing healthcare had a personal health budget in the period?				
12. How many adults receiving joint-funded packages had a personal health budget in the period?				
13. How many adults whose primary need is a learning disability and/or autism had a personal health budget in the period?				
14. How many adults who have a primary mental healthcare need had a personal health budget in the period?				
15. How many other adults not included in the four sub categories above had a personal health budget in the period?				

Pointers to support data submissions:

- Question 1 in the data collection is asking for **live/open PHB's on the first day the quarter**, this data should not include PHBs that ended before the first day of the quarter or financial year. For example, on 1 April 2018, only the current PHBs that are open on that date will be counted in this question.
- Question 4 is asking for all PHBs delivered within the financial year to date any PHBs ended within the year to date should still be included in this figure (until the next financial year)
- Question 4 we would expect will have a higher number than question 1
- Sub group questions are also asking for year to date information similar to question 4. Once all data is input for quarter 1, then each quarter the new PHBs should be added to the data for question 4 through to question 15 until the end of the financial year.
- When collecting data from external providers the relevant sections of the template could be sent to ensure that the data received matches data requests